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Mauro Turrini

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## Practicing the biomedicine to come: Direct-to-consumer genetic testing, healthism and beyond

**Mauro Turrini**

Université Paris 1 Panthéon-  
Sorbonne, France

[mauroturrini@gmail.com](mailto:mauroturrini@gmail.com)

[www.univ-paris1.fr](http://www.univ-paris1.fr)

[academia.edu/mauroTurrini](http://academia.edu/mauroTurrini)

### Abstract

As a device aimed at expanding the medical discourse by empowering patients, direct-to-consumer genetic tests (DTC GT) represent an ideal case to study through the prism of healthism. Indeed, this critical theory has anticipated many of the issues that the last generation of consumer personal genomics services have raised in the late 2000s. In particular, it frames the unnecessary anxiety that these diagnostic devices with a low or absent clinical utility may engender in a broader critical understanding of the spreading of medical rationality into everyday life. Giving access to health-related data bypassing any medical mediation is a way to normalize and discipline laypeople, even those who are not ill, by charging the responsibility for their own health.

At the same time, the ethnographic analysis of users' practices sheds light on the limits of healthism. Rather than generating new forms of responsibility and duties, users approach personal genomic data with curiosity and irony. The indeterminacy of this information, too, is not seen uniquely as the cause of a low clinical utility, but also as something that makes it to interpretation, circulation and combination. Personal genomic data are a means of a (potentially endless) discovery of one's own genetic self and kinship. In addition, the body fragmented in bio-data can be mobilized and recombined through Internet, as shown emblematically by the practice of "sharing the personal genome", which is used as a means to take part to new biomedical practice and even research initiatives. If healthism can be used as a critical framework of a "post-disciplinary" medicine spontaneously adopted by laypeople, it has not anticipated the meanings and practices related to the production and sharing of huge amount of bio-data, especially in terms of active participation in a possible model of future medicine.

### Keywords

Direct-to-consumer genetic testing, bio-data, healthism, biopolitics, biosociality.

## Pratiquer la biomédecine à venir: Autotests génétiques et santéisme

### Résumé

En tant que dispositif visant à élargir le discours médical en responsabilisant les patients, les tests génétiques en accès libre sur Internet représentent une étude de cas idéale pour cerner le santéisme. En effet, cette théorie critique a prévu bon nombre des questions que la dernière génération des services de génomique personnelle a fait survenir à la fin des années 2000. En particulier, elle cerne l'anxiété inutile que ces dispositifs de diagnostic présentant une utilité clinique faible ou même nulle peuvent engendrer dans une compréhension critique plus large de la propagation de la rationalité médicale dans la vie quotidienne. Donner l'accès aux données relatives à la santé en contournant toute médiation médicale est une façon de normaliser et de discipliner le grand public, même les personnes qui ne sont pas malades, en leur imputant la responsabilité de leur propre santé.

Toutefois, l'analyse ethnographique des pratiques des utilisateurs met en lumière les limites du santéisme. Plutôt que de générer de nouvelles formes de responsabilité et de droits, les utilisateurs considèrent les données génomiques personnelles avec curiosité et ironie. L'indétermination de ces informations, aussi, n'est pas entendue uniquement comme la cause d'une faible utilité clinique, mais aussi comme quelque chose qui stimule l'interprétation, la circulation et la combinaison. Les données génomiques personnelles sont un moyen de se découvrir soi-même de manière potentiellement infinie. En outre, le corps fragmenté en bio-données peut être mobilisé et recombinaison à travers Internet, comme le montre de manière emblématique la pratique du « partage du génome personnel », qui est utilisé comme un moyen de prendre part à la nouvelle pratique biomédicale et aux initiatives de recherche mêmes. Si le santéisme peut être utilisé comme un cadre critique afin d'analyser un médicament « post-disciplinaire » adopté spontanément par des individus, celui-ci n'a pas anticipé les significations et les pratiques liées à la production et au partage de la quantité énorme de bio-données produites, en particulier en termes de participation active dans un modèle possible de médecine à venir.

### Mots-clés

Tests génétiques en accès libre, bio-données, santéisme, biopolitique, biosocialité.

## **Practicando la biomedicina por venir: la prueba genética directa al consumidor, salutismo y más allá**

### **Resumen**

Como un dispositivo destinado a ampliar el discurso médico mediante la potenciación de los pacientes, las pruebas genéticas directas al consumidor (PGDC) representan un caso ideal para estudiar a través del prisma de salutismo. De hecho, esta teoría crítica se ha anticipado a muchas de las cuestiones que la última generación de consumidores de servicios de genómica personales ha planteado a finales de la década del 2000. En particular, se enmarca la innecesaria ansiedad que estos dispositivos de diagnóstico –con una utilidad clínica baja o ausente– pueden engendrar en una comprensión crítica más amplia de la difusión de la racionalidad médica en la vida cotidiana. Dar acceso a los datos relacionados con la salud sin pasar por ninguna mediación médica es una manera de normalizar y disciplinar a los legos, incluso aquellos que no están enfermos, mediante el cobro de la responsabilidad de su propia salud.

Al mismo tiempo, el análisis etnográfico de las prácticas de los usuarios arroja luz sobre los límites de salutismo. En lugar de generar nuevas formas de responsabilidad y deberes, los usuarios se acercan a los datos de genómica personal con curiosidad e ironía. La indeterminación de esta información, además, no es vista únicamente como la causa de una utilidad clínica baja, sino también como algo que hace a la interpretación, la circulación y la combinación. Los datos genómicos personales son un medio de un (potencialmente infinito) descubrimiento del propio yo genético y del parentesco genético. Asimismo, el cuerpo fragmentado en bio-datos puede ser movilizado y recombinado a través de la Internet, como se muestra emblemáticamente por la práctica de “compartir el genoma personal”, como un medio para formar parte de una nueva práctica biomédica e incluso de iniciativas de investigación. Si salutismo puede ser utilizado como un marco crítico de una medicina “post-disciplinaria” adoptada de forma espontánea por los legos, no ha previsto los significados y prácticas relacionadas con la producción y el intercambio de gran cantidad de bio-datos, especialmente en términos de participación activa en un posible modelo de la medicina del futuro.

### **Palabras clave**

Prueba genética directa al consumidor, bio-datos, salutismo, biopolítica, biosocialidad.

## 1. Introduction

As a device aimed at expanding medical discourse by empowering patients, direct-to-consumer genetic tests (DTC GT) represent an ideal case to study through the prism of healthism. In fact, the critical theory known as “healthism” pre-empts many of the issues that the last generation of direct to consumer genome-wide online testing services stimulated in the late 2000s. The debate escalated in the end of 2007, when the Californian 23andMe and the Icelandic deCODEme, soon followed by other two North-American companies, Navigenics and Pathway Genetics, introduced the first direct-to-consumer online whole genome decoding services. They provided people that had Internet access, a credit card, and the ability and willingness to part with several hundred dollars, information on their genetic risk regarding ancestry as well as dozens, and soon to be hundreds, of physical and biological traits and diseases.

DTC GT have dramatically changed the role and place of genomic information, especially health related data. Once restricted to people considered “at risk”, and conducted within specialized clinical centres at the prerogative of the medical professionals, clinically applicable genomics have crept into society. This information is usually in a digital format and, therefore, holds an increased capacity to propagate. Some commentators praised the possibility of sequencing one’s own genomes as a very effective *patient empowerment* tool, which would provide access to otherwise unavailable genomic research advancements. Journalists, writers, geneticists and researchers of other disciplines wrote articles and even books, celebrating these medical devices as marking “the dawn of a new era” (Angrist, 2010; Duncan, 2009; Pinker, 2009). Sceptical, and at times openly hostile, reactions came from scholars’ in academic journals (Caulfield & McGuire, 2012; Howard & Borry, 2008; Hunter, Khoury & Drazen, 2008; Lancet, 2008), professional associations (American College of Obstetricians and Gynecologists [ACOG], 2008; American Society of Human Genetics [ASHG], 2007; European Society of Human Genetics [ESHG], 2010), and governmental agencies (Agence de la Biomédecine, 2007 in France; and Government Accountability Office [GAO], 2010 and Secretary’s Advisory Committee on Genetics, Health, and Society [SACGHS], 2010 in the US) which deemed DTC GT an irresponsible *marketization of biomedical research* in need of increased regulation. This initial criticism focused on the reliability of the data delivered, by raising issues about their “technical validity” (to what extent are the data produced by these tests accurate?) and “clinical validity” (to what extent are their clinical meanings accurate?)<sup>1</sup>. This dispute was due, in part,

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<sup>1</sup> For a reconstruction of the regulatory and bioethical debate on DTC GT focused mainly on the questions inherent to technical and clinical validity, cf. Curnutte & Testa (2012).

to the fact that companies did not sequence entire genes, but used only single base pair changes, technically called “single nucleotide polymorphisms”, or, more simply, SNPs. These data were interpreted following a new branch of research, GWAS, “genome-wide association studies”, based uniquely on statistical associations between genetic markers and diseases, rather than a causal genetic explanation of a disease. Given the statistical nature and the newness of these studies, it is easy to imagine that there was, and still there is, no consensus about how to clinically interpret the data they generated. In a very famous editorial published in *Nature*, a team led by Craig Venter and colleagues indicated major genomic result discrepancies between the two leading companies of that period, 23andMe and Navigenics (Ng, Murray, Levy & Venter, 2009).

Yet, the most tenacious critique did not regard the tests’ clinical validity, but rather their clinical utility. In a rather disappointingly way, genomic research showed that for many complex conditions, genetic factors played a relatively minor role. In addition, due to the fixed nature of genetic markers, their impact on risk assessment was usually very low, if not absent. Does it really matter if one’s risk of getting prostate cancer increases or decreases by 10%, if there is nothing (or very little) one can do to decrease this figure? Is it really useful to know that one is susceptible to a certain condition, if the only available intervention for lowering risk is limited to adopting healthier behaviours like physical exercise and not smoking? The only effects that such information may engender, it has been argued, is unnecessary anxiety or false reassurance about predisposition to certain diseases. Thus, genomic information has often been deemed not only useless, but also potentially dangerous for individuals, possibly encouraging medical overtreatment. Due to these concerns, on November 22<sup>nd</sup> 2013, the U.S. Food and Drug Administration (FDA) sent to 23andMe a warning letter in which it ordered the company to cease providing health-reports to new customers. In particular, it argued that these tests had not been approved as a medical device:

intended for use in the diagnosis of disease or other conditions or in the cure, mitigation, treatment, or prevention of disease, or (...) intended to affect the structure or function of the body.<sup>2</sup>

The letter went on to list all the adverse consequences that genomic health-related data might induce if released without medical advice, such as undergoing prophylactic surgery,

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<sup>2</sup> Passage from the FDA warning letter, which is retrievable from [www.fda.gov/ICECI/EnforcementActions/WarningLetters/2013/ucm376296.htm](http://www.fda.gov/ICECI/EnforcementActions/WarningLetters/2013/ucm376296.htm) (retrieved on June 2015). For a more general reconstruction of this episode, cf. Wagner (2013).

chemoprevention, intensive screening etc., and/or changing or abandoning certain therapies depending on the outcome of the assessment.

This debate evokes one of the questions at the heart of healthism, which contains and elaborates several of the criticisms raised by the opponents of consumer personal genomics (PG). According to healthism, social attitudes or movements committed to reducing the power of medical institutions by giving an important role to the patient, as in the case of DTC GT, may end up producing the paradoxical effect of extending the medical gaze to society. Users lacking adequate expertise, spontaneously take the medical responsibility of their own health in their hands, may incur new duties and moral quandaries, which can result in serious psychological effects and a useless burden for healthcare systems. After discussing the validity of healthism as a critical theory, I will then move on, in the second part of the article, to comment on its analytical limits. A critique of many consumerist trends in contemporary health and wellness prevention and pursuit, healthism proves unable to grasp some of the specificities of innovations like PG based on an increased production of (and a more direct access to) health-related data. In particular, healthism cannot fully account for some of the emerging forms of sociability developed in bionetworking. To conclude, I will try to re-frame some aspects of this theory.

## **2. The right, and the duty, to know: Consumer personal genetics and healthism**

As expressed by one of its leading theorists, Robert Crawford (1977; 1980), healthism is a critical theory that intends to describe ideology and practices aimed at augmenting personal health and wellbeing outside of the medical institution. In this sense, healthism can be understood as a “form of medicalization” (Crawford, 1980) that distinguishes itself by focusing on processes that *occur outside the medical establishment, often contesting it*. The core of their criticism highlights not quite the extension of medical jurisdiction to traditionally non-clinical domains (as the theory of medicalization does), but rather critiques the propagation of non-experts’ (lay people) ways of perceiving and acting on medical-like objects. Healthism is therefore still an extremely current critical instrument for addressing prevention and health care

trends as well as a concept of well-being based on the patient's feelings, knowledge and choice, and, in particular, the wide range of patient-consumer and patient empowerment practices<sup>3</sup>.

The bearing on consumer PG is evident. DTC test are a social innovation more than a scientific one, which consists in challenging the medical prerogative to request, and therefore interpret cure-oriented laboratory data. One could talk at length about the social value of the medical expertise monopoly, but what I intend to point out here is the extent to which DTC contests this. This form of patient empowerment is all the more disruptive, in that it refers (playing on the second part of acronym, GT) to genetic information. In bioethics, the notion of "genetic exceptionalism" (see, e.g., Nelkin & Lindee, 1995) is used to indicate the exceptional status of genetic data due to its immutability, identifiability and transmission by inheritance. The availability of genetic data as well as of information technologies poses a challenge to it. The mediation of the Internet has facilitated not only access to data, but also the ability to compare one's data with others' and scientific literature. Both companies and users have created user-friendly platforms through which one can catch up on publications that relate to the genetic characteristics of the individual customers. In essence, the mediation function of the medical profession has been bypassed twice; both in access to clinically significant data, and in the relationship between research and practice. The following (personalized) e-mail sent to all the users of 23andMe highlights the value attached to this "revolution".

Just fifty years ago, doctors were reluctant to tell patients if they had cancer. The world is different today. (...) As customer number 555,634, you are part of this unique group of one million people driving change. I celebrate you, your 23andMe story and the power of all of us today: #PowerOf1Million.

Signed by Anne Wojcicki, "CEO and Customer # 60

This expansion of the medical gaze does not refer only to a new category of people (non-experts), but also to a new sphere of intervention. Healthism is undoubtedly one of the first theories to highlight the role of the concept of lifestyle as a container for a medical vision of everyday and family life, establishing a link between health and behaviour that was later broadly taken up (cf., e.g., Blaxter 1990; Hansen & Easthope, 2007; specifically on DTC GT Lucivero & Prainsack, 2015). In most cases, the recommendations found in personal genomics health reports merely consist in healthy abstract principles, like not smoking, not eating fat, or in more tailored, but still quite general, tips about certain foods or physical exercises. The

<sup>3</sup> For the relationship between healthism and patient empowerment, see Bardy (2014) in this volume.



companies themselves play on the ambivalence of their status on the borders of healthcare. In order to remove their products from the severe jurisdiction of medical products, companies present their services as free-flowing commodities “for research and educational use only”<sup>4</sup>, to be exchanged in the context of a company-consumer transaction. Nonetheless, their websites publish stories of people who have improved their health and telling slogans about the clinical benefits of their services, such as the following: “Take charge of your health and wellness: let your DNA help you plan for the important things in life.”

DTC GT can also be considered a typically “post-disciplinary” medical device, which, although similar to, is different from the model described by the medicalization thesis. Like medicalization, healthism understands the trend towards individualization as a way to reduce complex social issues to individual, biological ones. Differently from it, however, the single patient becomes not only the privileged terrain of medical explanation and intervention, but the individual also plays a critical role in self-care. The individual is “the locus of perception and intervention” (Crawford, 1980, p. 371). In the case of genetics, it means that, although it is not possible to control the genes we have, we may be able to control the ways in which we respond to our genetic risk factors through a calculated, rational, and farsighted conduct. In “classical” clinical genetics, specific genes were associated *deterministically* with specific rare syndromes (the Mendelian “the gene for” model). New genetics has instead provided a framework for evaluating increased risk (the “susceptibility”) for widespread conditions – a “premonitory knowledge” that seeks to bring potential futures into the present according to Lock (2005). In a sense, DNA is still seen as immutable, but the conditions to which we are naturally predisposed are not. As diseases are located in our individual organism, one’s response is essentially individual. In sum, the individualization of etiology goes along with the individualization of illness responsibility.

A final aspect of healthism that is useful for understanding DTC GT regards implicit moral values. The revolution against medical paternalism that they sponsor implicitly puts wellness under our personal control. The *duty to get well*, which Talcott Parsons (1951) depicted as incumbent upon the sick role, becomes re-transcribed as the *duty to stay well*, which regards any *potential* sick person, albeit “asymptomatic”. The temporary and marginal deviant status concerning ill people shifts to a permanent and universal condition that encompasses potentially anybody as a future, although not yet diseased, patient. *The right to know also implies the duty to know*. We are not just talking about knowledge regarding actually present diseases, but also susceptibility to future disease in so-called asymptomatic patients, which therefore has a

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<sup>4</sup> As written in the Terms of Service of the leading global company of the sector, 23andMe. Retrieved on July 2015 from [www.23andme.com/about/tos/](http://www.23andme.com/about/tos/).

universal scope. In this manner medical knowledge demonstrates a post-disciplinary regulation, based on responsibility, autonomy and active participation in the management of one's own health. In this regard we can talk about a new frontier of citizenship, "healthy citizenship" (Sharon, 2014), whose boundaries are redefined in the light of the new rights/duties one holds regarding health and wellness preservation, promotion and optimization. This passage reveals a further hidden and coercive dimension of *patient empowerment*: the stigmatization of those who refuse to assume the standard responsible and informed behavior regarding their own disease (see, e.g., Callon & Rabearisoa, 2004).<sup>5</sup>

Patient empowerment, despite its promises, turns out to enhance the very power of medicine it intends to criticise. The energy that it infuses into self-care practices generates new forms of self-responsibility, rationality, and autonomy, which are described by several authors as laboratories of neoliberal entrepreneurial subjectivities (see e.g. Petersen & Bunton, 2002; Crawford, 2006). These criticisms have shown the imperatives, self-discipline and normalization that hide behind the rhetoric of patient empowerment and the democratization of health care processes. Adherence to health in the end becomes an imperative, a compulsion and, ultimately, a creeping constraint which, although not imposed by physical force, is no less incisive. In this sense, healthism anticipates many of the criticisms that have surrounded the whole phenomenon of self-care, and in particular, the direct access of patients to medical information via the Internet as a challenge to expert knowledge. It focuses on the assumptions and implications of offering a broad framework. It also expands on this criticism by showing how the process of health-care individualisation, which becomes self-care, corresponds to a paradigmatic change of thinking about our physical condition, body, and ourselves as mere individual biological organisms, rather than social beings co-evolving in and through society. However, healthism theory proves to be unable to grasp the experimental values and uses that the dissemination of medical information and, in particular, of biology and genomics, has afforded.

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<sup>5</sup> In this regard, it is interesting to note that public measures that are actually able to get people to behave more health consciously (such as penalizing taxes, or the de-prioritization of access to some treatments) concern the predisposition to certain diseases caused by harmful behaviours (such as food or overeating), but also genetic susceptibility to common diseases such as type 2 diabetes (for a review see Resnik, 2014).

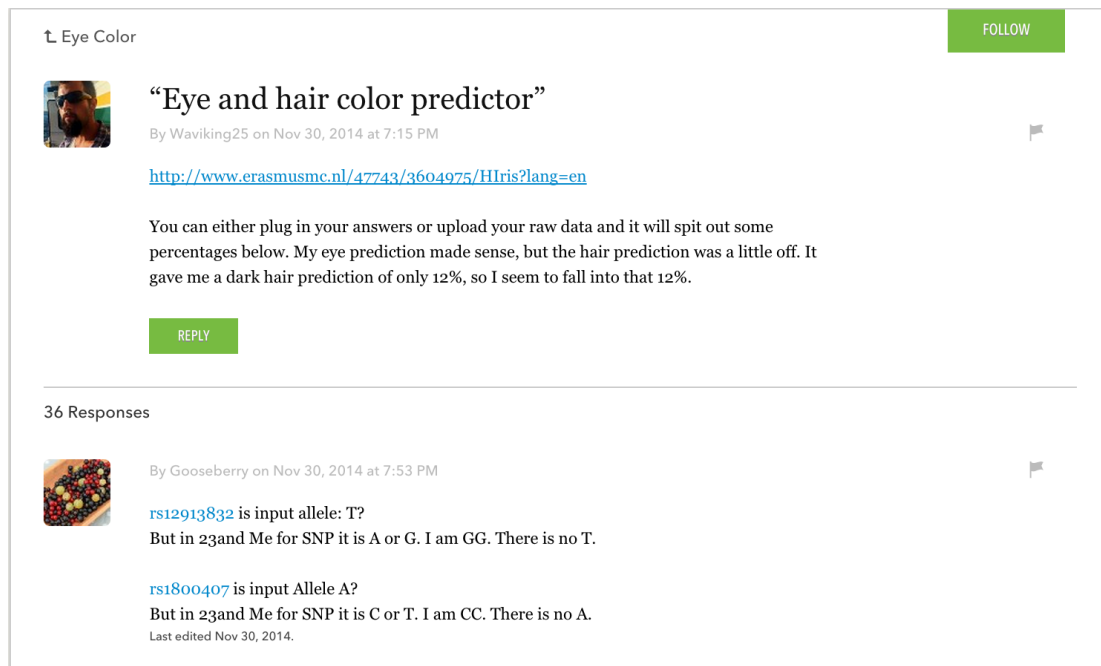
### 3. Beyond healthism: participation in and the future of personal genomics

An initial encounter with the research field displays a situation that displaces much of the critiques that we have examined thus far. As empirical studies have shown (see, e.g., Bloss, Schork & Topol, 2011; McGowan, Fishman & Lambrix, 2010), personal genomic health reports do not generate change in users' behaviour. Knowing one's susceptibility to a wide range of diseases does not induce them to adopt healthier lifestyles or to feel anxious. Yet, they do not feel cheated by the product they have bought, on the contrary, they are rather satisfied with the test results. This "paradoxical" superimposition of clinical uselessness and satisfaction lies at the heart of consumer PG and serves here as the starting point to reconsider the meaning of healthcare, medicine and body from the DTC GT users' perspective. The following empirical material was gathered in 2013-2015 primarily through a self-ethnographic experience as a 23andMe user (n. 555,634), a "virtual ethnography" (see, e.g., Hine, 2000) of the principal PG platforms (SNPedia, Promethease, Personal Genome Project, Interpretome, openSNP, DNAdirect...), forums, personal blogs, social media, as well as 24 semi-structured interviews with users.

An initial remarkable aspect is the curiosity users hold regarding the discovery of their genomic self. Information on so-called *recreational genomics* – about, for example, earwax type (wet or dry), muscle performance (sprinter or endurance athlete), hair colour, or bitter taste perception – is generally clinically irrelevant, and, yet, raises a lot of curiosity among users. There is a great interest in using the several interpretative tools to compare our genomic self with our "real" physical traits. Looking at the 23andMe forum on "Eye Color", we found several hundreds of people reporting on what they found out by interpreting their own raw data through several online, international open-access tools (devised originally for identification purposes, but re-appropriated by PG users; see the discussion in fig. 1). This discovery of the *genomic self* also includes the unveiling of family genomic inheritance. Users reflect on their personal situation and that of their families, seeking connections and similarities between relatives, reinterpreting certain symptoms, conditions or attitudes, and, in rare cases, coming up with a personal diagnosis or for a relative.<sup>6</sup>

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<sup>6</sup> This has been found in interviews by Prainsack and Vayena (2013, p. 406).



**Figure 1.** A discussion thread in the 23andMe forum on Eye Color, where a user suggests using an on-line software for interpreting raw data associated with eye colour. 23andme (2015). Retrieved on 10 July 2015 from <https://www.23andme.com/you/community/thread/33656> on July 2015.

Curiosity includes creativity in interpreting and combining different kinds of personal information with that of other users. The multiplicity and indeterminacy of personal genomic meaning is also related to a certain irony of personal genomic data. Users tend to play with their data. Some respondents speak of them as a "horoscope", others make jokes about the clinical implications. Commenting the 10% increased susceptibility to prostate cancer indicated by the genetic analysis, for example, an interviewee added: "Well... given the spread of prostate cancer, this was actually quite easy to foresee!" Another respondent, when asked about the information he received, spoke about his susceptibility to Alzheimer's. This, by the way, is one of the most delicate results due to the severity of the disease, the high predictability ("penetrance") of the genetic markers, and, in his case, evident familiarity with the disease. Still, at the end of the interview, when he was interrupted by the noise of a siren coming from the street, he joked about it by evoking his susceptibility to this condition: "I had it on the tip of my tongue, I wanted to tell you, but now I've forgotten... perhaps it's the beginning of Alzheimer's!"

Both this irony and curiosity show that personal genetic information, rather than generating new forms of responsibility and duties, is marked by a semantic indeterminacy which makes its open to interpretation, circulation and combination. Even when genetic data are associated with initiatives that are directly related to health betterment, the need to connect

with other information is evident. An interesting example can be found in the discussion in the 23andMe forum on predisposition to prostate cancer, and the harmful effects of milk. "It's milk", reads the title of the thread, presenting the personal theory of one of the users. The user uses a large body of literature from epidemiology, and science of nutrition to homeopathy to draw a correlation between growth hormone IGF-1 and prostate cancer. The reactions that this argument elicits are very diverse, ranging from those who reject it *in toto* to those who agree with it but for different reasons. The defenders of milk argue that the quality of the milk itself makes a difference. Those who support the theory that milk is harmful particularly for prostate health, come to the original conclusion but believe other nutrients in milk, such as calcium, are the cause of the harm. What is at stake is not only behaviour, i.e. removing dairy products from the diet, but is also linked to an interpretation of healthy lifestyles, in which the genomic information is only a piece and not a necessarily the cause. Personal genetic data is not evidence with a deterministic value, and yet their indeterminacy affords a more active engagement by users, a crucial difference that healthism does not recognize. This difference is particular evident when it comes to participation.

If healthism refers to "participation" in terms of self-responsibility, in DTC GT "participation" evokes something different that has do with the plural processes that create meaning for this information. Irony and curiosity surrounding genetic information do not imply an interiorization of the foucaldian "clinical gaze" (Foucault, 1973), as Crawford (1977) suggests, but rather an epochal rupture that moves towards the model based on networking, communication redesign rather than medicalization and normalization (see, e.g., Haraway, 1991).

Reducing the body to biodata also means creating new opportunities to share and compare this data. According to this process, defined as "bio-sociality" by Paul Rabinow (1992), biological makeup serves as the starting point for the shaping of identities and new subjectivities, especially when connected to illness, vulnerability or susceptibility. In an information society, the hyper-production of data does not function as a normalization and/or a discrimination process, but it rather implies new opportunities to mobilize, share and combine them. A conception of life inspired by the depth of the inner anatomical body cedes ground to a paradigm built on the reduction of life to information – a process which can not be fully achieved. The resulting "life itself" (Rose, 2007) may then propagate, link, and create networks. In particular, this concept has been widely used to analyse new forms of patient activism in the process of knowledge production marked by a willing to experiment with biology (Gibbon & Novas, 2008). In the case of the consumer PG, the concept of biosociality could be useful to better understand the forms of participation that develop from the shortcomings, multiplicity

and compositional potential of genetic information. As abstract information about life, genetic data must be specified in a manner that is found only through the association with family histories and new interpretative models.

Clearly, the temporal horizon here takes a signification which cannot be limited to healthism. On the one hand, health-related genetic data is an anticipation of the future, a horoscope, providing clues through which one can read certain changes, warnings (such as loss of memory, for example), and, ultimately, drawing on the title of a English reality show dedicated to DTC GT, addressing *The Killer in Me*. On the other, this future becomes more general and it involves something greater than the individual.

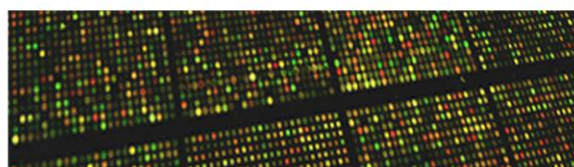
It's a kind of scary because it is so new and because I sent it a sample of spit and they can tell me I'm at an increased risk for prostate cancer. It is a little bit frightening, but... scary or not, this is the future!

In a similar manner, another user decided to socialize his decision to take the 23andMe test by posting a picture of the kit with the caption: "I tested the future". If genetic tests reveal the limits of providing personalized predictions of ones own genomic destiny, they seem much more effective in offering the opportunity to participate in the more general trend concerning the emerging healthcare model based on genomics and biotechnology innovations. Users, even if they show caution in interpreting their predisposition to certain diseases, are much more optimistic in considering the genome a pillar of future biomedicine. They buy into the "economy of promises", an aspect that biotechnological sectors share with financial markets (Sunder Rajan, 2006), while by "sharing" one's personal genomic data they intend to have a share in this economic and scientific enterprise. *Sharing* is intended here in the broad sense, in that it potentially involves everyone, at least those that can access the Internet. In essence, people donate their own genome so that it can be compared to others, in order to facilitate the progress of biomedical research. These genomic repositories intend to resolve several issues. Genetic information alone is not significant; it acquires meaning only when compared with other genetic and clinical information. At the same time, due to its identifiability and immutability, DNA is a particularly delicate information with respect to privacy protection. If the genome is a promising research field which will likely give great impetus to biomedical research, its use is problematic because it requires a series of cautions and precautions in order to protection individual privacy. Sharing genomes is a practice that aims to overcome this impasse through the voluntary donation of one's own DNA in databases that collect thousands of other volunteer

data, and could also collect also other information such as the physical traits and clinical history of the volunteers.

This practice started on the heels of consumer PG, in 2005, when the Personal Genome Project was founded, with the aim of creating an open-access, online data repository with the whole-genome sequencings of ten thousand volunteers. In any case, DTC GT significantly accelerated this practice. The market leader of this sector, 23andMe, has made sharing a central aspect of their service, even developing an advanced systems of surveys of clinical information, articulated through specific questions ("Quick questions"), questionnaires on specific aspects that last from ten to thirty minutes (on themes as different as "smoking and tobacco", "asthma", "understanding other people", or "longevity"...), and finally, important initiatives that revolve around the creation of a research community of patients suffering from certain diseases, such as Alzheimer's or sarcoma. Alongside this database, which is undoubtedly the most numerous database constructed from DTC GT user data, there are many other spontaneous initiatives, founded in the wake of the ideology inspired by sharing and open-access, which I will briefly address. OpenSNP is a web-platform that collects and provides genetic and clinical information to several thousands of volunteers who agree to participate in the project for the benefit of biomedical progress (see fig. 2). GenomesUnzipped is a molecular genetics blog, which provides articles of members and outside guests, as well as members' genetic data sequenced by four different companies. SNPedia is a wiki-style encyclopaedia that collects literature on genetic markers sequenced by DTC genetic companies, but also publishes genomes of participants.

### Welcome to *openSNP*



*openSNP* allows customers of direct-to-consumer genetic tests to publish their test results, find others with similar genetic variations, learn more about their results, get the latest primary literature on their variations and help scientists find new associations.

[Sign Up!](#)[Download the data!](#)[For Genotyping Users](#)[For Scientists](#)

Upload Your  
Genotyping File



Upload the raw genotyping  
data from your test

Share Your Phenotypes  
& Traits



Phenotypes are the  
observable characteristics of an organism

Share your stories on  
variations &  
phenotypes



Find literature on  
genetic variation



*openSNP* gets the latest  
primary literature on genetic variation

**Figure 2.** OpenSNP's (2015). Retrieved on 10 July 2015 from <https://opensnp.org>.



The deviation from classic forms of participation linked to the voluntary, anonymous and public sector tradition described by Richard Titmuss (1997) is evident. For the first time, we see research participants who pay for having the information they provide in order to secure a stronger control over it (Prainsack et al., 2008). This form of participation implies the creation of new subjectivities “who (are) addressed through a discourse of democratisation and empowerment, and who (have) the right to information as a value in itself” (Tutton & Prainsack, 2011, p. 1090). Whereas the emergence of enterprising subjectivities is also pointed out by healthism, the practice of sharing genomes brings a completely different relationship with the body and healthcare into play. The individual is divided into a multiplicity of data, which are then rearticulated through digital repositories. Freely accessible, spontaneously generated and up-to-date data repository are important for biomedical research. Some authors (Harris, Wyatt & Kelly, 2012) consider the construction of these repositories as new forms of “clinical labour” (Cooper & Waldby, 2014). Instead of projecting the clinical gaze onto specific individual symptoms, genome sharing indicates a link between consumer PG and health care, focused on the future and how to participate in the biomedicine to come. At the same time, literature on clinical work seems to describe these participative models as “post-disciplinary” forms of work organization and the creation of value. These immaterial economies do not only produce and exchange immaterial commodities such as information, but also depend on the promise of an imminent achievement in the field of biomedicine due to the accumulation, sharing and interpretation of genetic data.

#### 4. Conclusions

Healthism is an extremely far-sighted theory, and to some extent still contemporary with regards to the criticism of the extension of medicine outside of the clinic. While developed almost forty years ago, it is still a very useful theory with which to grasp the ambivalence between patient empowerment and disciplinary control, which lies at the heart of DTC GT. In particular, this analytical framework targets those practices that, taking its cue from a critique of medical paternalism, mobilize rhetoric focused on patient empowerment and democratization of medicine. To endlessly optimize and extend one’s health and wellbeing involves a personal responsibility that ends up extending the vision and values of clinical medicine to increasingly wider areas of private (daily and leisure activities, diet) and public (civic values of citizenship)



life. Such a critique is still sharp politically, but it fails to recognize some fundamental facets of the contemporary processes of change in the realm of healthcare and self-care. In particular, consumer PG shows its limits to understand the processes involved in a broader trend towards the increase in production of, and access to, health-related bio-data.

In contrast to the concerns posed by both healthism and its critics, the values that users attribute to health-related genomic data do not imply a *direct and immediate* clinical application. Consumer PG seems to be associated with a healthcare model that insists not so much on the responsabilization of the individual, as on the active role in the process of understanding and using data. Rather than evidence of a specific diagnosis or treatment, personal genomic data are a specific kind of information that has more than one meaning, which can be used in more than one context, and for more than one person or aim. The curiosity towards information related to our physical and mental condition and for which meaning is still being developed, as well as the irony displayed towards the interpretation of statistical correlations, are aspects that seem to indicate a deviation from the clinical paradigm, particularly evident in the new model of participation in biomedical research. Sharing one's own genetic data is a way to participate collectively to their signification process and, so, to the progress of biomedicine. If it is clear that the clinical utility is still the ultimate goal, it is not possible to dismiss the willingness to be part, experience, share, and so, be aware of and, in case, refuse the transformations of biomedicine.

This raises serious issues regarding discourses centred on the individualization and moralization of these processes. Obviously there are consumer PG services that provide as much clinically relevant as possible, and that does not envisage any activity of sharing, such as the Belgian company Gentle. We can not fail to highlight, however, also in this case, the availability of recreational information about physical traits, as well as the attention paid to the user display and browsing software. Even more interesting is that irony, curiosity and participation are at the heart of the market strategy of the company, 23andMe, which won the competition with other PG companies like Navigenics or DeCODEme and which is the current world sector leader. In addition to the participatory methods that we have already discussed, the genetic marker discussion forums, social networks methods that bring genetic relatives together, the choice of indicating in the report diverse results from earwax type (wet or dry), to ability to taste bitterness, the predisposition to Alzheimer's, or even the opportunity to learn one's genetic proximity with celebrities such as Napoleon, or extinct species such as the Neanderthals, seem to lean in this direction. This aspect, of course, makes us reflect on how a more active involvement (played out in the sphere of interpretation, and not only on the responsibility) is at the centre of strategies to involve people in a new health discourse based

on risk factors. In addition, sharing and participation in research may result in new forms of labour mobilization and value extraction related to the production, mobilization and interpretation of genetic data, which may be coupled with clinical information, but also freed from privacy restrictions. However, it is hard to dismiss these forces as mere consumer forms of post-disciplinary control, nor can we underestimate the opportunities that the production and sharing of bio-data generate in terms of active participation in a possible model of future medicine.

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